Retiring the term AIDS for more descriptive language

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The term acquired immunodeficiency syndrome (AIDS) was coined to describe a condition marked by weakened cell-mediated immunity in the absence of a clear cause. Due to unfortunate messaging during the early days of the HIV epidemic, this term became loaded with stigma. After the discovery of HIV, the term AIDS became redundant, but its use has persisted and has come to embody negative connotations in the current landscape of the HIV epidemic. People commonly associate AIDS with a terminal illness. This misconception promotes stigma by others, including health-care workers, but also self-stigma, which can prevent individuals from accessing health care. Also, the link between AIDS and gay men generated during the early epidemic with use of the term gay-related immune disorder is misleading regarding which populations are at risk, which can delay diagnosis. The use of the term AIDS is now discouraged by several professional associations, some of which ironically have the word as part of their name. Ending use of the term AIDS would not eradicate stigma. However, this term has outlasted its usefulness, and we should transition towards more descriptive language that aligns with contemporary challenges in HIV.

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Introduction

The term acquired immunodeficiency syndrome (AIDS) was coined by the US Centers for Disease Control and Prevention (CDC) in 1982 to describe a condition affecting individuals with weakened cell-mediated immunity, without apparent reason for immunosuppression.[1] The Nobel Prize-winning discovery of HIV just a few years later solved the mystery of what caused the disease, enabled the development of life-saving treatments, and allowed substantial improvements in quality of life. After four decades, persistent use of the term AIDS for the advanced stage of an infectious disease illustrates the profound and enduring impact a single word can exert on both the general public and health-care settings. Such a term fulfilled its purpose many years ago, but its continued use today represents a failure to keep up with scientific and social advances.

The early path of AIDS

The 1981 reports of *Pneumocystis jirovecii* pneumonia and Kaposi sarcoma among previously healthy young men were poorly managed by mainstream media.[2] Sensationalist, discriminatory, and stigmatising headlines were used by high-profile media outlets that heavily emphasised the sexuality of those affected.[3] Given that immunodeficiency was suspected early on, the unfortunate label of gay-related immune deficiency (commonly shortened to GRID) was initially used to describe this unknown disease.[3] Once it became clear that blood products could result in transmission of the disease (eg, plasma for haemophilia, or sharing equipment among people who inject drugs), the CDC introduced the term AIDS.[1] The initial use of AIDS was well justified: it was a case definition for a newly identified condition, continuously evolving while more information became available.[1] AIDS was a broad, descriptive term for people with no evident cause of immunosuppression (literally, an acquired immunodeficiency syndrome), and not specific to gay men. Nonetheless, due to a general lack of understanding and failure to correctly communicate information, AIDS became a stigmatising label for a population that was already facing discrimination.[4]

The causative agent of AIDS was identified to be a retrovirus in 1983 and was named HIV in 1986.[5] In 1987, WHO established the Special Programme on AIDS as a global response to the epidemic.[6] Jonathan Mann, the founding director of the Special Programme on AIDS, gave a powerful statement by declaring there were three interconnected epidemics: that of the AIDS-causing virus, the disease itself, and society's reaction to both. Although Mann's remarks did not explicitly underscore that the primary epidemic was that of HIV and not AIDS, his declaration did acknowledge (mainly due to the efforts of activists) the stigma embedded in society. Nevertheless, AIDS remained a pervasive term. The first posters of the Special Programme on AIDS emphasised the word AIDS with a skull.[6] Additionally, in 1987, the CDC modified the AIDS case definition to include over 20 so-called AIDS-defining conditions.[7] Such early decisions made AIDS a persisting term heavily loaded with stigma.

The 1993 CDC classification slightly expanded on AIDS-defining conditions and included CD4 cell counts to stage the disease, which renewed the apparent usefulness of the term AIDS.[8] The authors of the update emphasised that the cause of AIDS is HIV. However, this view asserts that AIDS is a distinct entity from HIV, whereas AIDS is actually an advanced phase of HIV infection.[9] AIDS was coined when nothing was known regarding the preclinical stage of HIV infection and when clinical features were not known to be caused by HIV. Once the natural history of HIV was understood, AIDS became a redundant term, given that it is an avoidable stage of untreated HIV and never a separate entity.

Is the term AIDS still useful?

Because AIDS originated as a case definition, its main use was in the context of epidemiological surveillance.[8] People with AIDS were typically those individuals with several years of delayed diagnosis of HIV; thus, the

concept was used as a marker of HIV infection at late diagnosis. However, the term AIDS can also include people who are diagnosed but not accessing care, as well as those individuals without or with intermittent access to antiretroviral therapy (ART), which makes the term non-specific to late diagnosis. Articles published in the past 10 years still include AIDS-defining conditions to describe opportunistic infections and neoplasms observed in people with advanced HIV.[10] However, considering AIDS alone as an indicator might oversimplify the complexity of HIV infection. An asymptomatic person with a CD4 count of 190 cells per µL at diagnosis would be considered to have AIDS, as well as a person with 10 cells per µL and cryptococcal meningitis. The latter represents a person with much more advanced disease and worse short-term and long-term prognosis. Additionally, not all AIDS-defining conditions are of similar severity. In today's clinical setting, it is essential to identify which opportunistic infections or HIV-associated neoplasms are present in each individual, and to know their CD4 cell count at diagnosis, to initiate the appropriate prophylaxis or directed treatments needed in good time. These decisions cannot be made by only categorising an individual as having or not having AIDS, which exemplifies the futility of the term regarding medical decisions. Moreover, in the treatment-as-prevention era, our main objective as health-care professionals should be focused on prompt diagnosis and initiation of ART as soon as feasible and acceptable, thus avoiding the development of advanced disease. Regrettably, many countries still face the challenge of late diagnosis (defined as diagnosis at CD4 counts of <350 cells per µL) in 50% of all new HIV cases, a situation that became worse during the COVID-19 pandemic.[11]

AIDS as an obstacle to HIV risk perception and testing

AIDS is perceived as a deadly disease and, by extension, people with HIV are seen as transmitters of a deadly disease. In some countries, stigma surrounding HIV can result from this perception of AIDS, and not exclusively from its link with sexual transmission and behaviours. In Africa, people with HIV are considered by some to be "dead before dying",[12] even among young individuals born in the era of highly active ART. This misconception enhances self-stigma, therefore preventing individuals from accessing testing, treatment, and follow-up care.[12] Self-stigma is also a problem in Europe. The European Centre for Disease Prevention and Control reports that self-stigma is present in 30% of people with HIV and that a considerable proportion of people are reluctant to look for health care due to fear of being stigmatised.[13] This self-stigma, as well as stigma exerted by other parties, is particularly prevalent among transgender women.[13] Some countries, such as China, heavily stigmatise the behavioural component behind HIV transmission, as those with sexually transmitted infections, including HIV, are excluded from job opportunities.[14] People with HIV are considered by some to deserve their disease.[15] This view is pivotal regarding the conceptual perception of HIV infection, because although AIDS is not the only source of stigma, it makes the perception of HIV as an irremediably mortal disease ever-present.[15] A 2021 study from Côte d'Ivoire found that unlinking HIV from the perception of death was paramount in novel HIV communication strategies.[16]

Continued use of the term AIDS and communication mistakes made during the early epidemic made this term an official label for people with HIV and introduced an association between the HIV epidemic, gay men, and (in some contexts) certain ethnicities.[4,17] As a result, in countries with concentrated epidemics, people who are not members of populations considered at risk are at risk of delayed diagnosis in advanced stages of HIV infection.[18] For example, in Latin America, where the HIV epidemic is concentrated in men who have sex with men, HIV diagnosis among cisgender women typically occurs during pregnancy, after stable male sexual partners are diagnosed with advanced disease, or after HIV is detected in newborn babies.[19]

Cisgender heterosexual men often have late diagnosis and worse prognosis.[20,21] In many cultural contexts where hegemonic masculinity prevails, the strong link between AIDS and homosexuality that was established during the early days of the HIV epidemic prevents cisgender heterosexual men from accessing HIV testing, affecting not only their prognosis, but increasing the risk of HIV transmission to their partners.[22]

Effective antiretroviral treatment enables people with HIV to have lifespans equal to that of the general population and high quality of life. Effective widespread treatment has also given rise to the principle that undetectable equals untransmissible (U=U). This current landscape of HIV is not reflected by the frequently used paired term HIV/AIDS, which gives the false impression that HIV and AIDS are equivalent or interchangeable. It is particularly important for the general public to be able to understand the difference. Australia has released resources for journalists to ensure they use the terms correctly given the potential to use AIDS as a pejorative term.[23] These examples emphasise the need to unlink AIDS from HIV, and specific sexualities and ethnicities. We consider the most direct way to achieve this separation is to end the use of the term AIDS altogether.

Language matters

Fortunately, language has progressively shifted away from the term AIDS. For example, the International AIDS Society-USA became the International Antiviral Society-USA, which issues guidelines on antiretroviral treatment for HIV.[24] The Joint United Nations Programme on HIV/AIDS has established the term

AIDS patient as stigmatising.[17] The People First Charter terminology guidelines, which are supported by numerous professional societies, also do not support the use of AIDS patient or other uses of the term.[25] Ironically, numerous professional societies and scientific journals have AIDS as part of their title while actively discouraging the use of this term. This lack of consistency should be addressed as changing titles has already been shown to be feasible. Thus, the use of this term across the scientific literature is erratic; it is still observed in some scenarios, as when referring to AIDS-defining conditions, while at the same time, agencies consistently discourage its use as stigmatising.[17,26,27]

Furthermore, the stigma associated with AIDS can lead to substandard behaviours among physicians who are unfamiliar with HIV care. For instance, reluctance to take care of people with HIV is associated with stigmatising and discriminatory beliefs.[28] Exaggerated infection control measures such as in-hospital isolation, use of additional hospital gowns and gloves, or advanced facemasks solely due to the person having HIV are further examples.[28] It is clear that these actions are not required, and might stem from an erroneous linkage of HIV and AIDS as terminal conditions.

Advocates for retaining AIDS terminology might argue that it has served a purpose in evoking fear, subsequently amplifying awareness and encouraging preventive actions within vulnerable populations. Nevertheless, evidence has demonstrated the contrary. Public campaigns based on fear can cause shock or shame and therefore prevent those at risk from accessing HIV prevention or care.[29] Conversely, conveying affirmative messages that explicitly outline effective HIV prevention methods, such as the impactful concept of U=U, empowers individuals to take control of their health and adopt self-care behaviours.[30] By proposing to move away from using the term AIDS altogether, we are not attempting to diminish the crucial requirement for disseminating lucid, assertive, and empathetic information regarding HIV infection to populations at risk. In the current landscape, it is more imperative than ever to ensure that HIV remains a focal point on the agendas of different stakeholders, including policy makers, public health experts, health-care providers, financiers, educators, physicians, and volunteers engaged with community-based organisations.

Taking into account the extensive historical context associated with its use, the term AIDS has evolved to function primarily as a label that perpetuates stigma and harmful beliefs (eg, HIV being an untreatable condition with dismal prognosis) that have been ingrained since its inception.[6] We propose that, at present, the term AIDS fails to provide specific guidance for health-care professionals and does little to contribute to effective care of people with HIV, so AIDS should not be used. Advanced HIV is a much more suitable alternative. Similarly, HIV/AIDS is detrimental by implying an equivalence that does not exist and can mislead the general population and health-care providers.

Finally, we consider it essential to clarify two points. This piece is not intended as a critique of the past; rather, it should serve as a suggestion of how we can move away from an archaic and non-informative term that only contributes stigma. In addition, it would be naive to assume that removing the term AIDS would suffice to eradicate stigma. Stigma is a pervasive issue that necessitates long-term education efforts and the promotion of health awareness. The term AIDS has outlasted its practical usefulness and we should transition towards more descriptive language aligned with the contemporary challenges posed by the HIV epidemic.

Contributors

IN conceived the manuscript. All authors jointly wrote the manuscript.

Declaration of interests

We declare no competing interests.

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